

Rachel Regitz.



Rachel is a beautiful 6 ½ year old little girl and is the youngest of four children. Rachel was born as a healthy, "normal" baby. She developed normally until she was 6 months old, but shortly thereafter, we began to notice that she was not doing the same things that our other three children had by 6 months of age. She stopped doing some things that she had already learned how to do as well. She wasn't trying to sit up, roll over, reach for toys, or making simple baby sounds (cooing) like she had been doing previously.

We had Rachel evaluated and were told that she had Cerebral Palsy. Within a month of that diagnosis, she started having seizures. A neurologist then diagnosed her with the rarest of all forms of Epilepsy called "infantile spasms". There is no cure for this type of epilepsy. We have tried every Epilepsy drug, including two from overseas, but none of them have helped Rachel has been in and out of various hospitals her whole life and has been poked and prodded too many times to count. In fact, she doesn't even flinch or make a sound when she gets a shot or has an IV placed in her arm. Her neurologist told us that Rachel will not live out of her childhood years. He went on to say, even if the seizures

completely stopped today, Rachel will still never walk, talk or do anything for herself, due to the brain damage which has already occurred. She is 6 years old, but developmentally she is like a 6 month old baby.

As she continues to age, her seizure types change each year. Every year they seem to get more violent. She has about 50 seizures per day, some more severe than others. Recently, we seemed to have settled into a somewhat "normal" life with 3 busy kids and one special needs child. That was until January 2008.

Rachel contracted a terrible virus that was not only affecting her breathing, but her left eye as well. Her pediatrician sent her to Texas Children's via ambulance where she was treated and sent home when her breathing improved. Several days later, the virus seemed to be gone, but the eye looked much worse. We took her to an ophthalmologist who then diagnosed her with "Ligneous Conjunctivitis". Ligneous is an extremely rare blood disorder that can permanently damage any of the mucosal organs. There are a hundred or so documented cases around the world, but only a handful of cases have ever been reported in the US. It's caused by a lack of plasminogen in the blood. Plasminogen is what the body uses to heal its wounds. Whenever Rachel gets a scratch or a cut, it takes a very long time to heal. Rachel is currently being treated by a Hematologist/Oncologist at Texas Children's Hospital who is trying to increase Rachel's plasminogen level by infusing her with fresh frozen plasma every two weeks. We have read about the many terrible things that Ligneous can do to a body and are very scared about what the future holds for Rachel. We thank God for her every day. She is such a joy to be around and has forever changed our lives for the better.

We are very thankful to the Bright Light Foundation for choosing Rachel to be one of the beneficiaries of this year's fundraiser. The funds will help us pay for the many things that insurance won't cover.

We can't thank you enough for your support.

God Bless You!
Jim and Amy Regitz.